

# The Caregiver

Newsletter of the Duke Family Support Program

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Summer 2006

## Co-Sponsored by

Duke University Center for  
The Study of Aging and Human Development  
N.C. Division of Aging and Adult Services  
Joseph and Kathleen Bryan  
Alzheimer's Disease Research Center

## Duke Family Support Program

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***Be Part of the Solution: Volunteer for Bryan ADRC Research***

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Subscriptions to this newsletter are available free to North Carolina residents. Call 800-672-4213.  
View this newsletter online at [www.dukefamilysupport.org](http://www.dukefamilysupport.org).

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**919-660-7510**  
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## Alzheimer's Association Contact Information

### Eastern North Carolina Chapter

400 Oberlin Road, Suite 220  
Raleigh, NC 27605  
919-832-3732  
800-228-8738  
awatkins@alznc.org  
[www.alznc.org](http://www.alznc.org)

### Caregiver Education Conferences

#### **Goldsboro**

*First Pentecostal Holiness Church August 22*

#### **Washington**

*Beaufort Community College Sept. 28*

#### **Henderson/Oxford**

*location and October date to be announced*

#### **Lumberton**

*Southeastern Agricultural Center, Hwy 74 Nov. 8*

For updated information and brochures, check  
[www.alznc.org](http://www.alznc.org), or call the office.

### Western Carolina Chapter

Main Office, Piedmont Region  
3800 Shamrock Drive  
Charlotte, NC 28215-3220  
704-532-7392  
800-888-6671 (24-Hour Helpline)  
[www.alz-nc.org](http://www.alz-nc.org)  
email: [info@alz-nc.org](mailto:info@alz-nc.org)

### Help Us Spread the Word

If you know of others who would find this newsletter useful, please tell them to call toll-free for a subscription. *The Caregiver*, published twice a year, is free to NC residents and \$10 per year for those out of state. Contact Mary Trabert, Program Coordinator, 1-800-672-4213 or [mary.trabert@duke.edu](mailto:mary.trabert@duke.edu).

### **Mountain Regional Office**

31 College Place, Suite D320  
Asheville, NC 28801-2644  
828-254-7363  
800-522-2451

### **Foothills Area Office**

260 1<sup>st</sup> Avenue NW, #218  
Hickory, NC 28601-4757  
828-267-7100

### **Triad Area Office**

1315 Ashleybrook Lane  
Winston-Salem, NC 27103  
336-725-3085

### Caregiver Education Conferences

Family, community and professional education programs are on-going. Call for a list of scheduled programs or to request a program.

**Alzheimer's Association Mountain Area Annual Caregiver Education Conference,**  
Blue Ridge Assembly, **Black Mountain.**  
November 9

Keynote Speaker: James R. Burke, MD, PhD, Associate Director, Bryan Alzheimer's Disease Research Center, Duke; Michael Splaine, Director, State Advocacy, Alzheimer's Association Public Policy Office.

### Outside North Carolina

**National Alzheimer's Association**  
225 North Michigan Avenue, Suite 1700  
Chicago, IL 60601-7633  
312-335-8700  
800-272-3900  
[www.alz.org](http://www.alz.org)

## Bryan ADRC 20<sup>th</sup> Annual Conference Highlights

James Burke, MD, Ph.D.  
Director, Bryan ADRC Memory Disorders Clinic

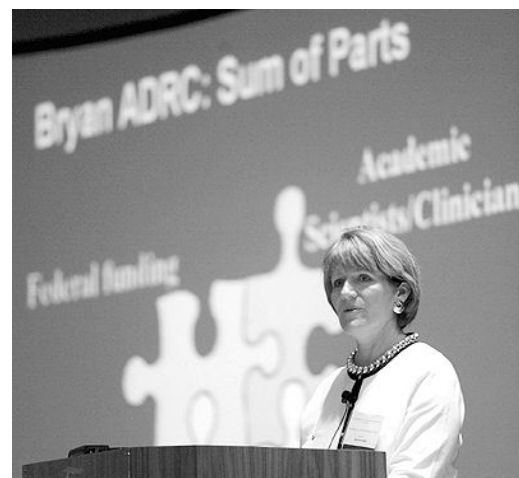
The scientific sessions at the twentieth annual Bryan ADRC conference were a rousing success presented by a creative and diverse multidisciplinary faculty. The presenters ranged from the first Bryan ADRC Director to the current Director. We learned of high tech science, new drug development and practical creative approaches for family caregivers and long-term care facility staff. And the creative approach to science was topped off with an original, world-premier musical highlighting the bittersweet story of a family struggle with Alzheimer's disease. A major theme of the conference was the critical role of research volunteers who spoke for themselves about the many unique opportunities to become part of the "solution" by participating in Alzheimer's studies.



Drs. Rosenfeld and Burke answer questions.

Dr. Rosenfeld, the first Director of the Bryan ADRC and now a senior vice-president at GSK led off the conference by highlighting the role of energy generation in Alzheimer's disease. He spoke of recent findings suggesting a key role for insulin signaling in Alzheimer's disease and noted that drugs that alter insulin signaling may be useful in treating Alzheimer's disease.

Dr. Kathleen Welsh-Bohmer, the new Director of the Bryan ADRC provided a vision for the future stressing the key role of genomics in understanding Alzheimer's disease. She noted that the current focus at Duke is on the study of normal aging and mild cognitive impairment as well as individuals with dementia. Dr. Welsh-Bohmer and the Duke team will be following a large group of individuals to understand better the genetic, medical and environmental factors that lead to dementia. She stressed that the relationship between the ADRC and research volunteers is a long-term partnership.



Dr. Welsh-Bohmer highlights the vision for the future of Bryan ADRC research.

Dr. John Morris, Director of the Alzheimer's Disease Research Center at Washington University in St. Louis, the conference keynote speaker, emphasized the positive by noting that Alzheimer's disease is not an inevitable consequence of aging and that Alzheimer's can be diagnosed and treated, even if it is not currently curable. He summarized tantalizing findings on a number of drug targets that may lead to the next generation of Alzheimer medications. The hope is that the next generation of medications will not simply treat symptoms, but will slow or stop disease progression.



**Dr. Morris is optimistic about future answers to Alzheimer's disease.**

Dr. David Goldstein, a geneticist at the Duke Institute for Genome Science and Policy at Duke and a key collaborator of the Bryan ADRC, explained how pharmacogenetics can be used to tailor medication choice using epilepsy as a model for future Alzheimer's therapies.

James Burke, M.D., Ph.D., the Associate Director of the Bryan ADRC and the Director of the Memory Disorders Clinic, spoke of the cognition continuum that ranges from normal cognitive abilities through mild cognitive impairment to dementia. He noted that mild cognitive impairment is not always the harbinger of dementia and that controlling risk factors like hypertension, diabetes and hypercholesterolemia might reduce the chance of decline.

David Steffens, M.D., a geropsychiatrist at the Bryan ADRC, spoke of new findings and approaches to the treatment of psychiatric symptoms in dementia. Dr. Steffens reported that psychiatric symptoms such as agitation, depression and apathy are common in Alzheimer's disease and may affect as many as 7 out of 10 individuals. Dr. Steffens suggested a staged approach to assessment before deciding to treat behavioral changes with medication. He offered the encouraging note that preventive interventions targeted at caregivers and the environment, de-escalation techniques, treatment of contributing causes and judicious use of medications can succeed in treating the vast majority of neuropsychiatric symptoms in individuals with dementia.

Dr. Linda Davis, a professor at the Duke School of Nursing summarized two elements of her research helping families manage memory and mood in individuals with dementia. Dr. Davis is one of two first distinguished research professors at Duke's School of Nursing and an expert in family caregiving research. She directs Project ASSIST, a National Institute on Aging funded

study testing different approaches to skills training and support for families caring for individuals with dementia. Dr. Davis focused on practical methods that improve the quality of life of all family members. She suggested using memory boxes to aid recall of common facts, such as identity of family members and location of home. She provided evidence for family caregiver benefits from relaxation exercises, calling a buddy and practicing positive self-talk.



**Drs. Steffens, Burke and Davis, and Mr. Troxel respond to participant questions.**

David Troxel, MPH, a long-term care consultant, discussed models of residential care that work. He stressed the importance of inclusiveness in workplace culture and the importance of training and encouraging all staff to have a say in day-to-day management. Mr. Troxel noted that the key goal of long-term care facilities is to individualize approaches to residents by encouraging staff to be less task-oriented and more person-centered.



**Raija Scheithauer, a Bryan ADRC "control" research participant talks with Dr. Welsh-Bohmer and Mari Szymanski, R.N.C.**



**Dr. Christine Hulette, Neuropathologist, welcomes participants to the Kathleen Price Bryan Brain Bank Tour.**

A uniquely rich and creative mix of workshops offered skills training for family and residential care staff, music therapy strategies, unique faith-health partnerships, practical information on driving, and a creative arts workshop featuring visual arts, a poet and a novelist. The ever-popular

“behind the exam room door” tour of the Memory Disorders Clinic and the over-subscribed Bryan Brain Bank Tour rounded out the program.

Special events in keeping with the conference creativity theme included the world premier of the musical “Forgotten Memories”, a tour of the new Duke Nasher Museum of Art, an organ recital at the famed Duke Chapel and the NC Festival of the Book’s opening lecture by Barbara Kingsolver.



**“Forgotten Memories”, an original musical, premieres at the Bryan ADRC 20<sup>th</sup> Annual Conference.**

## SAVE THE DATES

### For Next Year

21st Annual Bryan ADRC Conference  
Thursday and Friday

**March 1-2, 2007**

Durham Marriott at the Civic Center



**Networking and Discussion --- keys to a successful conference experience.**

## Clinical Trials at Duke



Do you suffer from  
Alzheimer's Disease  
or  
have a family  
member  
who suffers?

Duke University Medical Center is conducting  
a Research Study Exploring the Effects of an Investigational Drug  
on memory function in Alzheimer's patients.

If you would like more information about this study, please contact:  
**Dr. Burke at 919-684-5650 or  
Deb Heydt, Study Coordinator,  
at 919-668-2843**

IRB # 5743

## Duke Needs Brain Donors for Alzheimer's Disease Research

The Joseph and Kathleen Bryan Alzheimer's Disease Research Center at Duke University Medical Center needs brain donors who are:

- *at least 65 years old*
- *mentally alert*
- *live within 100 miles of Duke*

Arrangements for brain donation must be made well in advance of death.

Interested individuals should call Mari Szymanski, RN-C at:  
(919) 416-5388 or toll free at 1-866-444-2372



#0182

## Clinical Trials at Duke (continued)

**Individuals age 60 to 85 with no major medical illnesses** (i.e., stroke, heart disease, dementia, etc.) may be eligible to participate in a research project examining imaging technologies to detect brain patterns associated with Alzheimer's disease risk and potential memory problems in seniors. Free, confidential magnetic resonance imaging (MRI) scan and screening tests of memory and thinking. Compensation provided. Call (919) 416-5380 or toll free 866-444-2372. #7672

### CAREGIVERS NEEDED for UNC Study on Managing Medications

A research study is currently being conducted at the University of North Carolina School of Pharmacy to determine the difficulties that caregivers face when dealing with their loved one's medications. Caregivers of persons with memory problems are being recruited to complete a short study questionnaire and will be offered a small token of appreciation.

In order to participate in the study, the caregivers must be

- (1)  $\geq$  18 years old,
- (2) able to read and write in English, and
- (3) responsible for managing the medications for the patient.

If you meet these criteria and are interested in participating in this study, please call John Byrd at 919-674-2535 or email him at [jbyrd@unc.edu](mailto:jbyrd@unc.edu) and he will mail you a study questionnaire. Upon receiving the questionnaire, you will complete it (it will take you about 15-20 minutes) and drop it back in the mail using the self-addressed stamped envelope provided.

We do believe that your participation and responses will help us better understand the stress and burden of managing medications for dementia patients. It is our hope that the study will identify potential opportunities for pharmacy interventions for Alzheimer's patients and their caregivers. **This research aims to help caregivers. We will never understand the challenges faced by caregivers without the assistance of people like you!**

Thanks in advance for considering participating!

This research is conducted under the supervision of Betsy Sleath, PhD, UNC School of Pharmacy, Division of Pharmaceutical Outcomes and Policy, who can be reached at 919-962-0079. The study has been approved by the UNC School of Medicine Institutional Review Board (IRB Study Number 05-PPES-536).



## Of Daughters and Driving

By Sandra Hart Void  
Pittsboro, NC  
November 15, 2005



My mother was diagnosed with Alzheimer's disease at 71 years old. She is a widow after having been married for 52 years.

I can remember the first doctor visit when the word "Alzheimer's" was spoken. I was in a state of shock and disbelief. How could this woman of God, who was a retired preacher for 30 years, having served on political committees and built a church from the ground, be diagnosed with this disease?

The office visit was not pleasant. The worst of the worst happened not just to my mom but also to me. The doctor asked my mom for her car keys and then proceeded to give them to me and explain to my mother that her driving privileges have ended. I thought "Oh No". She is very independent and drives herself to church and everywhere she wants to go. I just knew after explaining that her church is less than 2 miles from her driveway that he would give her reduced or limited driving privileges. But it was to drive or not to drive and in the end, it was "not to drive". Mom's car keys were given to me and I had to drive her home and keep the car keys. Well, I felt a sense of betrayal. I said to her "I am going to leave these keys in the drawer and trust you to only drive to church." That made her happy. Wouldn't you know my older sister called and asked, "What did you do with the car keys?" I said, "I left them at the house." She said, "Well you have got to go get them because if Mom decides to drive herself somewhere and gets lost, it's your fault." I was dressed for bed and had to get up and go to Mom's and retrieve those car keys. My mom was angry with me for years. She would tell everybody ... "San took me to the doctor and took my car keys. San is the reason I can't drive."

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## Give a Caregiver a Break Essay Contest

*Caring Today* magazine with sponsor Home Instead Senior Care have announced the *Give a Caregiver a Break Essay Contest*. Caregivers, age 18 years or older, providing nonprofessional care for a person 65 years of age or older and living within the U.S., are invited to submit an essay in 500 words or less about their day-to-day experience of caregiving. One Grand Prize of \$5,000 worth of free care provided by Home Instead Senior Care and two First Prizes each worth \$2,500 of free care provided by Home Instead Senior Care will be awarded. Entries must be submitted online by 11:59 p.m. on July 15, 2006 or postmarked by July 15, 2006 and mailed to Essay Contest, c/o Caring Today, 1465 Post Road East, Westport, CT 06880. For more information and to submit an entry online, go to [www.caringtoday.com/hicontest/entry.aspx](http://www.caringtoday.com/hicontest/entry.aspx).

**Editor's Note:** First-person stories from North Carolinians living with dementia and/or their families are always appreciated by *Caregiver* newsletter readers. We can't offer contest prizes, but **we do give you a voice**. Send your stories, poems, or tips to Lisa Gwyther, 3600 DUMC, Durham, NC 27710 or [lpq@geri.duke.edu](mailto:lpq@geri.duke.edu).

## Success Stories

## Former Duke Family Support Program Intern Honored



Juliessa Pavon and her mother.

Juliessa Pavon, a Duke graduate and former Duke Family Support Program Leadership in an Aging Society intern and volunteer, received the Edward Henderson Student Award at the national meeting of the American Geriatrics Society in May, 2006. This annual national award honors a student interested in a career in geriatrics nominated by two research faculty. The awardee demonstrates excellence and leadership in geriatrics research, scholarship and program innovation. The award included a \$500 travel stipend to attend the presentation at the American Geriatrics Society Scientific Meeting. Juliessa presented her original research on dementia and aging with Duke and National Institute on Aging research mentors at previous American Geriatrics Society and Gerontological Society of America annual meetings. She is currently completing her third year of medical school at the University of Florida Health Science Center. While at Duke's Family Support Program, she assisted with a study of disparities in caregiver stress and their health effects. It is reassuring to know that Juliessa will pursue her consistent goal of geriatric medicine as well as her specific interest in Alzheimer's disease research.

## Former Duke Aging Leadership Intern to Attend Harvard Medical School

Katy Lowry, a Duke graduate and former Duke Family Support Program Leadership in an Aging Society intern will begin Harvard Medical School in the Fall. Many Caregiver readers will remember Katy's newsletter feature on participation in Alzheimer's genetic family studies. Katy also worked with Lisa Gwyther for the NC Division of Aging and Adult Services on the web-based "Absent on the Job" research summary on the effects of family care on employment. Katy worked in research this year for Dr. Ann Brown, Duke Associate Dean for Women in Medicine and Science. We wish her well.

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## Ask These 3 Questions to Improve Your Health

Are you nervous asking your doctor, nurse, or pharmacist questions? Don't be. Everyone wants help with health information. You are not alone if you find things confusing at times. Your medical team wants you to get the information you need to care for your health. Here are three good questions to ask whenever you go to an appointment, prepare for a procedure, or get your medicine.

- 1) What is my main problem?
- 2) What do I need to do?
- 3) Why is it important for me to do this?

If you ask these questions and don't understand the answers, let your doctor, nurse or pharmacist know. You might say, "This is new to me. Will you please explain that to me one more time?" Asking questions helps you understand how to stay well or get better. Read more at [www.askme3.org](http://www.askme3.org).

## Of Fathers and Sons \*

By Tommy Hays  
Asheville, NC



One problem had been that Daddy had been falling out of his twin bed at night. We had borrowed a child's guard rail from the Endicott's, which had kept him from rolling out but in the middle of the night he often crawled to the end of the bed and fell out. And since he was far too heavy for her to lift, more than once Mama had had to call the neighbors at 2 a.m. to help her get him back into bed. So Chris had decided to make Daddy a double bed out of the twin bed in the guest room and the twin bed Daddy had used to sleep on upstairs, hoping that with more room he'd be more comfortable and less likely to try to crawl out.

Chris had in mind a comfortable, makeshift bed Allison's parents, who own a bed and breakfast in Vermont, had fashioned from a particular kind of foam rubber and the box springs of two twin beds. True to his architect's nature, Chris thinks of life in terms of projects, and he threw himself headlong into this one, immediately going upstairs to move Daddy's old bed downstairs. I followed him.

He went back to Daddy's bedroom and began to lift the heavy mattress. "You want some help with that?" I asked, starting to take hold of the other end of the mattress.

"I can do it myself," he said, picking up the mattress and then teetering with it down the stairs. Then he came back up for the box springs.

"You sure you don't want help?"

"It's easier to do it alone," he said, grunting as he wrestled the box springs through the bedroom door and then bumped it down the stairs.

"Maybe for you," I said to myself, as I stood in the stifling heat of Daddy's office and just looked around at the shelves of books, stacks of brochures and magazines he'd designed, sketchbooks filled with meticulous renderings of women, notebooks filled with notes on his artwork, and here and there little piles of mail, much of it unopened.

I pulled Peter Mathiessen's "Snow Leopard" off one of the shelves--a book my father and I had both really enjoyed. I flipped through it, smelling the stale cigarette smoke. I had taken several books back to Asheville over the years that had been shelved up here, and they all still smelled of cigarette smoke. Daddy's books, his papers, his clothes were all soaked with years of his smoke, as if every object exuded his breath. ...

As I stood there not knowing where to begin, I envied Chris the focus and clarity of his project down below. A familiar malaise settled over me. It was the same kind of feeling I used to get sitting at the supper table with Daddy. My arms and legs felt heavy, as if the room had too much gravity. I could hardly move. I might have lain down on Daddy's bed if Chris hadn't already hauled it downstairs.

One thing that made me uncomfortable was the stealth. I was going through Daddy's things as if he were dead instead of downstairs in the living room watching baseball. We hadn't told him we were cleaning out his rooms because we were afraid it might upset him, and probably he wouldn't have wanted to throw anything away. I felt a little like I did when, every few months, while the children were at school, I took a garbage bag and went on a Happy-Meal, party-favor toy purge in their rooms.

The other thing that made me uncomfortable was the fact that I had been waiting to do this all my life. All my life Daddy's various offices in our various houses had been full of mystery to me. As a child, I had often stood outside his office just listening to him type. His office was the place he'd worked, where he'd written, drawn, read, meditated. It was the place he had "researched the great religions of the world." My father was his office, and now I finally had my chance to try to piece together who he was and what exactly he had been up to all these years.

I heard the industrious scrape of furniture downstairs. Chris was energetically rearranging the guest bedroom. Unconsciously, my brother had abandoned me to our father's history, left me alone in the wilderness of his words. ...

Then I found a yellow note pad, which was nothing but pages and pages of Daddy's signature. "Thomas Franklin Hays" written over and over and over. At first, I didn't understand. But then I realized Daddy had had to practice signing, and to make it even more heartbreaking, the pen he was writing with began to lose ink, so that the signature became fainter and fainter, until on the last page all you could see were indentations. Daddy had been up here panicked that he, a man of books and letters, had forgotten something as elementary as how to sign his name. And over the weeks, as I continued cleaning upstairs, I would find sheets tucked in books or behind shelves with his signature rehearsed a dozen or more times. I would see his shaky, halting handwriting and remember his strong bold signature which he used to sign our report cards, the huge dramatic "T" taking up half the page.

As I began to slowly sift through the papers, which had collected over the years, I felt like an archaeologist sifting through sediment. I found copies of personal letters he'd revised dozens of times, crossing out sentences, penning in other phrases. I found one long letter he had written to me about his religious beliefs fifteen years ago, except that it was addressed to Ben Julian, a friend of his. The only differences were that he had substituted "Dear Tommy" with "Dear Ben..." and changed the dates. As I glanced over the letter, which was really more of a treatise on his mysticism, I felt cheated that he'd sent someone else a letter he had initially written for me. But later, thinking back on it, I wondered if Daddy had used the letter he'd written me because, by the time he'd met Ben Julian, he was no longer able to write about his beliefs.

I organized and boxed up Daddy's letters and copies of his work and his art and his photographs, and I threw almost everything else away. The more I cleaned, the better I began to feel. I was restoring order to my father's life, **editing out the chaos**. And, like Chris, I was getting something done. The hardest thing about watching Daddy's demise was watching it. So it was a relief to take action, even if what Chris and I were doing was more for ourselves than anyone else. When the father falls apart, the sons get busy.

\* Lisa Gwyther chose this title for this excerpt from Tommy Hays' original essay titled "Out of the Woods: An Essay about Losing My Father." The essay was originally published in the Atlanta Literary Magazine, The Chattahoochee Review. His personal experience laid the groundwork for his successful novel, *The Pleasure was Mine*. Tommy read from his novel and distributed his essay at the Bryan ADRC 2006 20th Annual Conference in a very successful workshop titled "Creativity, the Arts and Alzheimer's Disease." We are grateful for his permission to reprint this reflection.

## Response to 'A Moral Dilemma: A Caregiver's Decision'

By Nancy Allan, BSW  
Virginia Beach, VA  
December 29, 2005



Dear Barbara,

*I recently read your article, "A Moral Dilemma: A Caregiver's Decision" in the fall 2005 edition of The Caregiver. I was very moved. I admire you for your honesty and courage, as it is a difficult subject.*

*I am also the primary caregiver to my mom, who will be 91 in March 2006. I am fortunate because she can still spend the day alone while I work full time, but her short-term memory is certainly failing. I hope I will be able to recognize when the time comes that she needs to have someone with her all the time. I am a social worker working with older persons and their families, so I should know what to expect, but **when it involves my mother instead of a client, things can be less clear.***

*Our moms have some things in common – painful arthritis, high blood pressure and dementia. Mom's bilateral cataract surgeries a year ago improved her eyesight, but her hearing is very diminished and she detests wearing her hearing aides. She prefers to stay put in her favorite recliner, resists going out of the house, but she seems to avoid getting depressed because she is still able to read large print books and work her word-find puzzles.*

*I wonder how things would be if her dementia gets notably worse. She wears a Lifeline pendant, but has not had to use it yet.*

*My mom's side of the family has longevity with two of her sisters living into their nineties. She has one 92-year-old sister left, in a nursing home in New Jersey. My mom is thrilled to be alive as she became a great-grandma for the first time in July when my daughter (who lives 5 minutes from us) gave birth to twin boys. As happy as she is to be able to hold the babies, I am finding it harder to make time to be with her because I go to my daughter's house frequently. I feel guilty leaving my mother alone more now, yet I so much want to help with my grandsons.*

*I facilitate a caregiver support group. I have heard several caregivers voice their concerns that their elderly parents may well live into their nineties. I think **many of us are wondering how many more years we can continue to be caregivers, yet we are reluctant to admit that out loud.** Like you, I sometimes resist/question doctors' suggestions/recommendations re: her health care. She is very reluctant to take any more meds than she is already on, so she refused to try a new medicine that might have slowed her dementia. She doesn't want to return to an arthritis specialist for a 3<sup>rd</sup> set of cortisone shots in her knees. The last set didn't help, and she really doesn't want to have to struggle to go to an appointment.*

*As much as I love my mother and as wonderful as she has been to my two kids and to me, I sometimes wonder why we live so long. Mother is in pain from her arthritis and spinal stenosis. She misses out on so much because she can't hear what's going on. She has so little energy, and she has lost most of her family and friends. She adjusted pretty well to the loss of my dad in 1995 – he had severe dementia and she was a patient caregiver to him. We lost my only sister a year ago due to complications of multiple sclerosis and mental illness. Her death hit my mom hard. In 2000, my sister's only son was killed in a motorcycle accident, and that, too, affected us all.*

*My mom is still very pleasant and sweet, so I am very fortunate. She can still get to the bathroom herself with a walker. She can even fix herself lunch, although her appetite is very diminished. Things could be so much worse. I try to remember that day to day, but I feel guilty when I find myself resenting her presence or the responsibilities I have because she's living with me. Then I feel bad. I wonder if she'd be happier in an assisted living facility with people around all the time, but I know she would prefer to be with my cat and me. Hopefully I will be able to keep things going as she progresses.*

*I didn't mean to tell you my life story. Mostly, I wanted to applaud you for writing an incredibly truthful article that will certainly make a lot of people look at things differently and hopefully better understand the problems we face as those we care for live into old, old age.*

## The death of a thousand subtractions

By Henry Walker  
Durham, NC  
November 10, 2005

as dusk moves through this Piedmont autumn  
I lose my view of the colors just now peaking,  
those translucent leaves  
with rich reds and golden yellows at their heart  
who richly glow before us for awhile  
till time and wind pluck and scatter them across the land,

I sit here with pen and paper poised  
to write about the frustration  
of how long Mother's goodbye is taking,  
that death of a thousand subtractions,  
the time after time of reading the signs  
that death is just around the corner,  
the scurrying around to prepare  
words and pictures to capture and celebrate her life,  
videotapes of her casting out words  
to net what she can of what she has done to be who she is,  
The pulling together of a funeral service that will honor her and help us,  
the making sure that resource and care are there for her  
to keep her at home, comfortable and appreciated,

I sit here, and avoid,  
with all the wily evasion I can,  
I avoid looking inside, clear enough,  
to where I'm ready for her to go,  
this week when I tell others  
of her pulling herself back from the brink, again,  
their quick response is thankful and relieved,

I don't have a quick response like that,  
I am tired and I cannot understand just why she is holding on,  
she's slowly starving  
and she has few bridges left  
for either her or us to cross between her reality and ours,

The Hospice nurses don't know how she is holding on  
and none of us, no matter how close, any longer know why,

it seems like it's time for her to let go  
and I fight letting myself  
feel that  
think that  
say that,

the leaves are leaving the trees,  
and it's time,

and I still struggle to endure with her  
while she keeps finding the way to not yet cross over.

"Mother passed away peacefully this morning... She was ready to go."

## **The Magnificent Journey**

By Henry Walker

Durham, NC

December 7, 2005

now when I think of Mother  
I see her smiling, full of life,  
wrinkles drop away, eyes animate,

she quickly heads out the door to see the bear,

local politics prod her to the typewriter for a letter to the editor,

she bustles about the kitchen whipping up angel biscuits and chicken salad,  
and the coffee should be hot and fresh,

I see her after Gatlinburg's city council meetings  
working friends and councilmen at the cabin  
with cake and coffee and a push for the city to do better,

I sleep late while I know she's downstairs  
taking care of our kids with doting attention and whole-wheat pancakes,

she delights in watching the kids play in the creek  
and in any company who will drop by,

every meal on the porch a celebration of family and friends  
and how good food can be:

I see her slice another piece of cake "just to even it up,"

I drive with her to the cabin to get it ready for renters so we can afford to keep it,

I see Daddy and Mother welcoming people to rent rooms  
when Gatlinburg motels run out of space, all because money was so tight,

I see her at Nag's Head, at the Old Swimming Hole, and at Edisto:  
bathing cap and suit on and loving the water,

I see her intense at the piano and hear  
"believe me, if all those endearing young charms. . ."

I see her in her classes teaching the cook,  
the literature and writing student,  
yet really the whole kid  
for whom her school was not designed as well as she encouraged,

I see the twinkle in her eye and the joy in her smile when we kids did well,  
and the indulgent pride when she got me to dance to the radio when I was just  
small,

just 3 hours ago she was taking her last breaths,  
for years that vibrant woman, whom I now see so clearly,  
has been obscured by Alzheimer's fog and wasting,

she would not yield  
but she could not stop the distance  
pushing itself  
between us  
and that so alive woman I see so clearly now,

she's finished the hike and left the mountain of her life,  
I see her last steps  
yet I also see the magnificent journey of all her steps before.

---

**Esther S. Angley Glover**  
**Feb. 12, 1924 – April 14, 2006**

**My loving wife of sixty years passed away at two AM Friday morning**

By George C. Glover  
Lenoir, NC

She had been going down hill much faster within the past three months. I went to the rest home Sunday April 2<sup>nd</sup> to eat lunch and visit with her. I tried to feed her but she would not open her mouth to eat and would not suck on a straw to drink. She was not responding to anything I said or did to get her to eat or drink. The nurse worked with her and did get her to swallow some dessert.

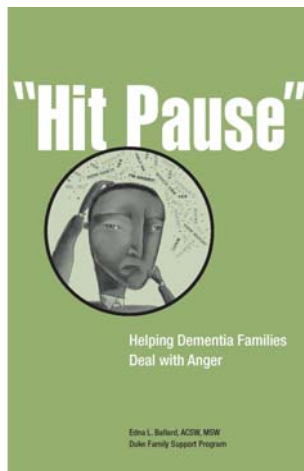
I went back on Thursday April 6<sup>th</sup> in the afternoon; she was in bed but not asleep. She was moving around but did not respond to me talking to her in any way. The nurse put her in her wheelchair. I sat beside her holding her hand for an hour, but she never made any indication she knew I was there. This was the end of our lives together.

They called me from the rest home Tuesday morning April 11<sup>th</sup> at 4 AM to let me know they were taking her to the hospital ER. Later that day a nurse at the hospital called and asked how far I wanted to go to keep Esther alive. I told her to go by the living will which states no hookups. Charles (our son) stayed with her until 10 PM Tuesday night. The hospital was going to transfer her to Hospice Wednesday morning, but the doctor told Charles she would not live over twenty-four hours. She lived until 2 AM Friday morning.

This has been such a great relief to me knowing Esther is now at peace. I think of her all the time, but I have no regrets and no guilty feelings. Esther and I had a wonderful life together and made many great friends as we traveled over the years.

Thank you for your support and for publishing my articles in the past. I am going to the Support Group meetings hoping I can give others advice and be of some comfort to them.





## “Hit Pause”: Helping Dementia Families Deal with Anger

Edna Ballard, MSW, of the Duke Family Support Program and the Education Core of the Bryan Alzheimer’s Disease Research Center, recently completed the third in Duke’s series of materials about Alzheimer’s and anger.

- **Pressure Points: Alzheimer’s and Anger** (2000) by Edna L. Ballard, Lisa P. Gwyther, and T. Patrick Toal is a paperback book for families available for \$8 pre-paid to Duke Family Support Program, 3600 DUMC, Durham, NC 27710.
- **Wait a Minute!: When Anger Gets Too Much** (2003) is a fold-up brochure of quick reminders for families available free on the Duke Family Support website [www.dukefamilysupport.org](http://www.dukefamilysupport.org) (click on “Links/Resources”) or for \$1 per copy (outside NC ONLY) pre-paid to Duke Family Support Program.
- **NEW: “Hit Pause”: Helping Dementia Families Deal with Anger** (2006) by Edna Ballard is a 12 page booklet for professionals and aging network staff working with Alzheimer’s or dementia families. Available for \$1.50 pre-paid (outside NC ONLY) or on [www.dukefamilysupport.org](http://www.dukefamilysupport.org) (click on “Links/Resources”).

The two latest brief materials were funded by the NC Division of Aging and Adult Services with grants from the Administration on Aging (AoA) for NC’s Family Caregiver Support Program and NC Project C.A.R.E. (Caregiver Alternatives to Running on Empty), an AoA Alzheimer’s Disease Demonstration Grant to States Program. The Administration on Aging’s Alzheimer’s Resource website also has the two brief pieces on their website. The National Institute on Aging’s ADEAR Alzheimer’s information program distributes *Pressure Points* as well.

Lisa Gwyther and Edna Ballard launched the statewide use of “**Hit Pause**” in a package with “**When Anger Gets Too Much**” on June 6, 2006 through the NC Family Caregiver Support Program interactive videoconference. Participants in this quarterly videoconference are Area Agency on Aging and county family caregiver resource specialists, Alzheimer’s Association staff, NC Project C.A.R.E. staff and others gathering at one of eight university videoconferencing centers throughout NC. Aging network and Alzheimer’s service providers were encouraged to use the family brochure and the brief professional booklets as a package in working with families in all service settings.



## Web Sites

[www.ahrq.gov/consumer/surgery/surgery.htm](http://www.ahrq.gov/consumer/surgery/surgery.htm) new publication *Having Surgery? What You Need to Know* to help patients make informed decisions when planning for surgery. Also available in Spanish.

[www.alz.org/brain/overview.asp](http://www.alz.org/brain/overview.asp) Inside the Brain: An Interactive Tour.

[www.alz.org/Downloads/DementiaCarePracticeRecommendations.pdf](http://www.alz.org/Downloads/DementiaCarePracticeRecommendations.pdf) free download of "Dementia Care Practice Recommendations for Assisted Living and Nursing Homes" (2005).

[www.alzheimers.nia.nih.gov](http://www.alzheimers.nia.nih.gov) the new site of the National Institute on Aging's Alzheimer's Disease Education and Referral (ADEAR) Center (formerly [www.alzheimers.org](http://www.alzheimers.org)).

[www.asaging.org/cdc/module6/home.cfm](http://www.asaging.org/cdc/module6/home.cfm) free download "Physical Activity for Older Adults: Exercise for Life."

[www.caregiver.org/caregiver/jsp/content\\_node.jsp?nodeid=1500](http://www.caregiver.org/caregiver/jsp/content_node.jsp?nodeid=1500) new dementia fact sheet from the Family Caregiver Alliance National Center on Caregiving.

[www.caregiving.org/pubs/brochures.htm](http://www.caregiving.org/pubs/brochures.htm) just published 5th edition of *Aging Parents and Common Sense: A Practical Guide for You and Your Parents* and *Aging Parents and Common Sense: A Directory of Resources for You and Your Parents*, developed with assistance from the National Alliance for Caregiving, available in pdf format.

[www.caringinfo.org/planningahead](http://www.caringinfo.org/planningahead) *Planning Ahead: Understanding Your Health Choices Before a Crisis*, a free consumer education course. Offers advance directives downloads by state.

[www.dhhs.state.nc.us/consumerdirectedsupports/](http://www.dhhs.state.nc.us/consumerdirectedsupports/) North Carolina Department of Health and Human Services "toolbox" of materials to help consumers plan and control the services that enable them to remain in their communities. Includes guides for individuals, families and providers of care.

[www.ftd-picks.org](http://www.ftd-picks.org) Association for Frontotemporal Disorders (Philadelphia) has excellent information for caregivers. Toll free 866-507-7222.

[www.geriatricsatyourfingertips.org](http://www.geriatricsatyourfingertips.org) 8<sup>th</sup> edition of a popular clinical guide to care for older adults published by the American Geriatrics Society.

[www.healthlawyers.org](http://www.healthlawyers.org) the American Health Lawyer's Association's "Guide to Legal Issues in Life-Limiting Conditions" is available for download.

[www.lifebio.com](http://www.lifebio.com) help writing a loved one's biography.

[www.lifemanagement.com/nextsteps](http://www.lifemanagement.com/nextsteps) covers topics including long-term care, Medicaid qualification, a patient's rights in nursing homes and hospitals, discharge and transfer issues, senior care, nursing home care, estate planning, retirement planning and protecting assets.

[www.naela.org/public/QA.htm](http://www.naela.org/public/QA.htm) "Questions and Answers When Looking for an Elder Law Attorney." (2005)

[www.nia.nih.gov/HealthInformation](http://www.nia.nih.gov/HealthInformation) the new address for previewing and ordering National Institutes of Health (NIH) publications.

[www.nia.nih.gov/HealthInformation/Publications/LongDistanceCaregiving/](http://www.nia.nih.gov/HealthInformation/Publications/LongDistanceCaregiving/) new publication "So Far Away: Twenty Questions for Long-Distance Caregivers."

[www.niapublications.org/pubs/talking/index.asp](http://www.niapublications.org/pubs/talking/index.asp) newly revised popular publication "Talking with Your Doctor."

[www.nlm.nih.gov/medlineplus/druginfo/herb\\_All.html](http://www.nlm.nih.gov/medlineplus/druginfo/herb_All.html) updated information on herbs and supplements from reliable NIH sources.

[www.nursingcenter.com/library/JournalArticle.asp?Article\\_ID=637530](http://www.nursingcenter.com/library/JournalArticle.asp?Article_ID=637530) provides techniques to make bathing a pleasant and comforting experience for older adults.

[www.strengthforcaring.com](http://www.strengthforcaring.com) Johnson & Johnson's Caregiver Initiative resource site.

[www.StrengthinCaring.com](http://www.StrengthinCaring.com) read first chapter of Strength in Caring: Giving Power Back to the Alzheimer's Caregiver free.

[www.stroudsymposia.org](http://www.stroudsymposia.org) an Alzheimer's Disease International website with comments about quality of life from persons with dementia.

[www.thehastingscenter.org/news/features/eoldecade.asp](http://www.thehastingscenter.org/news/features/eoldecade.asp) electronic copies of Hasting Center Report "Improving End of Life Care: Why Has It Been So Difficult?" and its executive summary.

[www.virtualhouse.novartis.com](http://www.virtualhouse.novartis.com) select disease (e.g., Alzheimer's) and room in the house to see safety suggestions for home care by room and individual risk or vulnerability.

---

*We could certainly slow the aging process down  
if it had to work its way through Congress.  
— Will Rogers*



## Have You Heard About?

- About Preparing Your Advance Medical Directives.* (2005) South Deerfield, MA: Channing Bete, CO. [www.channing-bete.com](http://www.channing-bete.com). Easy-to-read 16 page booklet explains advance directives and provides a checklist for preparing them. Price: \$1.15 each.
- Ball M, Perkins M, Whittington, F, Hollingsworth C, King S and Combs B. (2005) Communities of Care: Assisted Living for African American Elders. Baltimore, MD: The Johns Hopkins University Press.
- Beerman, S and Rappaport-Musson, J. (2005) The Eldercare 911 Question and Answer Book. Amherst, NY: Prometheus Books.
- Brawley, EC. (2005) Design Innovations for Aging and Alzheimer's: Creating Caring Environments. Hoboken, NJ: John Wiley & Sons, Inc. For families, architects, design professionals, and health care professionals offering practical, cost-conscious and aesthetic residential and group activity design solutions.
- Davidson, A. (2006) A Curious Kind of Widow: Loving a Man with Advanced Alzheimer's. McKinleyville, CA: Fithian Press.
- Drew L and Ferrari LC. (2005) Different Minds – Living with Alzheimer's Disease. Canada: Goose Lane Editions. 112 page book contrasting different perspectives of a husband with Alzheimer's and his wife as care partner.
- Kane RL and West JC (2005) It Shouldn't Be This Way: The Failure of Long-Term Care. Nashville, TN: Vanderbilt University Press. A personal narrative with lessons for both long-term care professionals and caregivers.
- Larsen, B. (2005) Movement with Meaning: A Multisensory Program for Individuals with Early-Stage Alzheimer's Disease. Baltimore, MD: Health Professionals Press. [www.healthpropress.com](http://www.healthpropress.com). Combines gentle dance movements, yoga-inspired poses, and breathing exercises with music, poetry, and other sensory activities for people with early-stage Alzheimer's.
- Lee, J. (2003) Just Love Me: My Life Turned Upside Down by Alzheimer's. West Lafayette, IN: Purdue University Press.
- McIntyre, C. (2005) Flowers for Grandpa Dan: A gentle story to help children understand Alzheimer's disease. St. Louis, MO: Thumbprint Press.
- Park, B. (2002) The Graduation of Jake Moon. New York, NY: Aladdin Paperbacks. Fiction. Teenage boy recalls the last four years watching his grandfather descend into Alzheimer's disease.

Peterson, B. (2004) Voices of Alzheimer's: Courage, Humor, Hope, and Love in the Face of Dementia. Cambridge, MA: Da Capo Press.

Silverstein NM and Maslow K (Eds.). (2006) Improving Hospital Care for Persons with Dementia. New York, NY: Springer Publishing Company.

Warner, ML (2006) In Search of the Alzheimer's Wanderer: A Workbook to Protect Your Loved One. West Lafayette, IN: Purdue University Press. [www.thepress.purdue.edu](http://www.thepress.purdue.edu).

**Correction:** The author of "The Amazing Move" in the Fall 2005 Caregiver is Gray McKay. We apologize to Ms. McKay for incorrectly reporting her first name in that issue.

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## Newsletter By and For People with Dementia Now Free Online

***Perspectives: A Newsletter for Individuals with Alzheimer's or a Related Disorder*** is edited by Lisa Snyder, LCSW of the Shiley-Marcos Alzheimer's Disease Research Center at the University of California, San Diego. Now in its 11<sup>th</sup> year, the 8-page quarterly newsletter written by and for people with dementia is available FREE by e-mail. Mail your request for a free e-mail subscription to: [lsnyder@ucsd.edu](mailto:lsnyder@ucsd.edu). (Print subscriptions are \$20 per year.)

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## Behind Closed Doors

By Virginia Parrish  
Hickory, NC  
April 9, 2006

Some say, "No way."  
Others turn away.  
Most stay away.  
Caring for a dying husband  
Is her responsibility.  
Her...being his wife.  
Don't have time to call, visit, pray.  
Too busy to care.  
Put it out of mind.  
Leave it...  
Behind Closed Doors.



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*At times our own light goes out and is rekindled by a spark from another person. Each of us has cause to think with deep gratitude of those who have lighted the flame within us.— Albert Schweitzer*

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